

in the future. UK GPs now need to redefine their role, bearing in mind that they have little or no control over other professions who are expanding their roles and providing services that GPs have decided to give up. There is a strong case for a broad debate about the future role of UK general practice.

#### Jim Cox

Medical Director of Cumbria Ambulance Service NHS Trust

#### Competing interests

Jim Cox is Medical Director of Cumbria Ambulance Service NHS Trust, a role which involves some direct patient care. He is a former GP and member of RCGP Council.

#### REFERENCES

1. WONCA Europe. *The European definition of general practice/family medicine*. WONCA Europe, 2002.
2. Department of Health. *The NHS Plan. A plan for investment, a plan for reform*. London: Department of Health, 2000.
3. Pickin DM, O'Cathain A, Sampson FC, Dixon S. Evaluation of Advanced Access in the national primary care collaborative. *Br J Gen Pract* 2004; **54**: 334–340.
4. Salisbury C. Does Advanced Access work for patients and practices? *Br J Gen Pract* 2004; **54**: 330–331.
5. Healthcare Commission. *Survey of patients 2005: primary care trust*. London: Commission for Healthcare Audit and Inspection, 2005.
6. Department of Health. *Attendances at accident and emergency departments and minor injury units, NHS organisations in England, 2004–05*. [http://www.performance.doh.gov.uk/hospitalactivity/data\\_requests/download/a\\_and\\_e\\_attendances/ae\\_05.xls](http://www.performance.doh.gov.uk/hospitalactivity/data_requests/download/a_and_e_attendances/ae_05.xls) (accessed 7 Sep 2005.)
7. National Statistics. *Ambulance services, England: 2004–05*. <http://www.dh.gov.uk/assetRoot/04/11/36/79/04113679.pdf> (accessed 7 Sep 2005.)
8. Department of Health. *Taking healthcare to the patient: transforming NHS ambulance services*. London: Department of Health, 2005.
9. Royal College of General Practitioners. *The future of general practice: a statement by the Royal College of General Practitioners*. London: RCGP, 2004.
10. Britnell M. On the on-call conundrum. *Health Serv J* 2005; **115**(5965): 17.
11. Avery A J, Pringle M. Extended prescribing by UK nurses and pharmacists. *BMJ* 2005; **331**: 1154–1155.

#### ADDRESS FOR CORRESPONDENCE

##### Jim Cox

The Barn, Caldbeck, Wigton, Cumbria  
CA7 8DP.  
E-mail: [jim.cox@btconnect.com](mailto:jim.cox@btconnect.com)

## Care of patients with intellectual or learning disability in primary care: no more funding so will there be any change?

*'Perhaps the unsuccessful treatment of these people and the hostility they face is a non-modifiable problem intertwined with the long-term outcome of learning disability and the inherent difficulty this disability poses on normal social functioning, rather than a problem with the institutions that provide health care and social services.'* (Mary Sheridan, 1965.)<sup>1</sup>

*'In the state of nature all men are born equal, but they cannot continue in the equality. Society makes them lose it and they recover it only by the protection of the law.'* (Charles de Montesquieu 1689–1755.)

As the UK financial year comes to a close partners, associates and practice managers will join eagerly together in assessing their Quality and Outcomes

Framework (QOF) figures and targets — practice, personal and national, financial, operational and clinical, and statistics and reports will enable us to make a final rush towards the March deadline. It is remarkable how some targets will drive us to intense activity while others lay forgotten. It would be interesting to know how many GPs reading this editorial work in practices where each of their learning disabled patients has had a health action plan composed for them with the help of a health action facilitator. It would be even more interesting to know how many practices are able to identify the number and names of patients on their lists suffering from learning disability.<sup>2</sup>

If intellectual ability were normally distributed among the population then those with an IQ 2 standard deviations below the mean would constitute 2.5% of the population. This would assume a

polygenic multifactorial form of inheritance and a normal distribution. There are few people with IQs at the upper and lower end of the distribution with most of us clustering around an IQ of 100.<sup>3</sup> The effects of birth defects, birth trauma, chromosome disorders and metabolic problems may cause a skewing downwards of the tail of the normal distribution. The incidence of learning disability is therefore estimated to be about 2%. The prevalence increased by 53% over the years 1960–1995 and will probably increase by 11% over the years 1998–2008,<sup>4</sup> so that the prevalence will be in the same region as hypothyroidism or diabetes, disorders for which care is resourced and outcomes are subject to QOF scrutiny. Medical intervention has unusual effects — the incidence of Down's syndrome might decrease as the result of antenatal

screening while learning disability from other causes increases as the result of increasing average maternal age and complicated deliveries. Health and social needs are not solely determined by the IQ, but also by the appearance, personality, behaviour and background of the patient.<sup>5</sup>

Discussions about learning disability are fraught with difficulties of definition. Even the term 'learning disability' provokes discussion and disagreement. The Department of Health advocates the use of the Read Code E3 which labels the patient with 'mental retardation', while many would prefer the term 'intellectual disability', which is used in much of current literature in the US and implies a more detailed description of the disability and is thought by many professionals to reflect more empathy and understanding of the patient's difficulties. Others would prefer the term 'learning difficulties' but no Read Code is available.<sup>6</sup>

A learning disabled person up to the age of 50 years has a mortality 5–8 times that of a non-learning disabled person.<sup>7,8</sup> Morbidity among the learning disabled is higher and also idiosyncratic: lung cancer and smoking related diseases being less common and gastrointestinal malignancies, epilepsy, sensory impairment, osteoporosis, hypothyroidism, diabetes, *Helicobacter pylori* gastrointestinal disorders and, remarkably, deaths from respiratory infections having a much higher incidence. Diabetes is five times more common within the learning disabled. Epilepsy is 25% more common; hearing and vision problems are 50% more common. Compounding this morbidity and high mortality is a social inequality predisposed to the moderately learning disabled by the high risk that they will have moderately learning disabled parents and the severe learning disabled by the fact that if their parents and other carers are looking after them at home they will be financially disadvantaged. In 2003 44% of families supporting a child with learning disability were living below the poverty line compared to 30% of other families with children. Only 29% of adults with learning disabilities of working age are in any form of employment.<sup>9,10</sup>

The move from institutional care to life

in the community resulted in the care of the learning disabled being devolved to primary care.<sup>11</sup> Those with this responsibility have no specific training in their care either at undergraduate or postgraduate level, in spite of pleas for it to be included in general medical education<sup>12</sup> and for research into the process and outcomes of care.<sup>4</sup> The practicalities and difficulties of caring for such a special population is therefore undertaken by doctors with no special training and no guidance from outcome studies. If prescription X, that requires as part of its monitoring a blood test every 3 months, will provide an extra year of life for a middle-aged severely learning disabled person with an estimated life expectancy of another 6 years, should it be prescribed considering that each of the 18 blood tests that patient is subject to will be approached in the same way most of our patients view colonoscopy without anaesthesia? Such ethical, moral and practical dilemmas need to be addressed against a background of uncertain and hesitant support from the carers — usually the parents. Such parents were given some counselling in the early years of their child's life by a paediatric team, which acted as a 'one-stop shop',<sup>5</sup> but along with adulthood came a disparate group of unrelated agencies and frequent changes of local and national policy. Bearing in mind the likelihood that the multifactorial polygenic nature of inheriting learning disability<sup>13</sup> means the parents are also likely to be learning disabled or troubled by the social deprivation which accompanies learning disability, it is not surprising that the two-way process of communication with them is frequently dysfunctional and some suggestions are met with suspicion, doubt or even the mirth that derives from previous experience.

When comment is made among healthcare workers about improving the provision and access to health care for the learning disabled emotive terms are often exchanged. These emotive exchanges often involve discussions about mammography and cervical cytology — how can these uncomfortable procedures be performed on learning disabled patients without them being

able to appreciate the value of preventative care or the risks or benefits? Physical deformities associated with learning disability are often quoted during such discussions to give emphasis to the difficulties with which these facilities can be offered to the learning disabled. To our mind the best way of dealing with such arguments is to be radical. It is to accept that there is a significant proportion of patients with learning disabilities who are so mentally or physically disabled or who would be so distressed by cervical cytology or mammography that it can not be justifiably performed. We, therefore, abandon any attempt to offer these services to this group of clients until ways of making them more user-friendly are created. Abandoning these two emotive forms for screening does not prevent us from eliciting the red reflex of all patients with learning disability looking for cataracts, of checking the ears of all patients with learning disability for wax and performing a simple hearing screen, of ensuring that all learning disabled and, in particular, those at high risk have regular thyroid checks, of ensuring that those caring for the learning disabled have adequate access to appropriate dietary advice relevant to the specific metabolic abnormalities which obviously occur in their disability but have not been yet fully assessed, such as in Prader-Willi syndrome or Down's syndrome. Vascular disease is more common among the learning disabled and no-one can justify withholding from them screening for hypertension, hyperlipidaemia and diabetes.<sup>10</sup>

Alongside access to adequate preventive medical care must go the more tailored provision of therapeutic care. For many years professionals have tolerated and cooperated with the maze through which a carer has to find his or her way in obtaining the appropriate aid or appliance, orthosis or communication aid. The resulting service would be considered farcical among commercial enterprises but it remains, producing increased difficulties to carers, particularly those caring for those older than the 'one stop' paediatrician can support, to the detriment of the quality of the life of the adult learning disabled. If a

patient with insulin dependant diabetes, 0.5% of the population, is admitted to a general surgical or medical ward specialist diabetic nurses supervise the patient's care in relationship to the diabetes. Surely the time has come for clinical nurse specialists in learning disability to be appointed to liaise with every practice, primary care trust, hospital ward or department to offer a seamless service to those bewildered by systems attuned to those with intellectual ability. Arrangements for admission, discharge and care at home would then be supervised and inspired by someone with experience of the particular needs of the learning disabled. Anecdotal evidence shows that where arrangements are made for a carer or relative to stay with an inpatient learning disabled adult the care is easier and there is less need for the use of psychotropic drugs.

The Disability Rights Commission is investigating the effect learning disability has on the standard of care offered to patients and their preliminary reports suggest significant inequalities in both practice and outcome.<sup>13</sup> General practice and the NHS are littered with documents ranging from *Once a Day*<sup>14</sup> to the more recent *Valuing People*<sup>2</sup> which, published in 2001, suggested that by June 2005 all practices would have a register of patients with learning disability, and all patients with learning disability would have a health action plan constructed for them and with them, with the help of a health action facilitator.

Contracts for locally or nationally negotiated 'enhanced services' that may include specifying a practice's duty to create a register may be counterproductive if the register is simply a number crunching experience. Distinguishing between moderate learning disability and normal can be difficult, particularly when the social situation of the moderate learning disabled patient is such that, through financial and family supplementation, any learning disability is compensated for. A simple definition of learning disability would be 'those patients registered with a practice who are using learning disability-related services' (North Warwickshire Primary Care Trust, unpublished data,

2002) or an alternative would be 'those patients who have associated with them another patient who considers himself/herself to be a carer because of learning disability.'

What is greatly needed is an increased sensitivity among the profession, and particularly general practice, to the needs of this deprived group to whom we can only offer unequal access and unequal facilities of health care. Practices, hospital departments and other aspects of the health service that learn to cater for the needs of the learning disabled can only move onwards and upwards along the stepladder to civilisation. In the words of the parent of a learning disabled adult:

*'Empathy, compassion and action must be the course which the doctor takes. A kind word can make all the difference and alter the course of another person's life.'*<sup>11</sup>

A step forward would be for our negotiators to have learning disability specifically included in the 2006–2008 QOF clinical indicators with a target of developing a practice-based register of patients with learning disability requiring additional support and a measure of what proportion of those had been offered and received an annual health check. Some have obtained the funding and indicated the way forward<sup>15</sup> and an article in this Journal demonstrates the benefits of such checks and possible further ways forward.<sup>16</sup>

#### Peter Lindsay

GP, The Thakur Practice, Yeadon, Leeds and member of the RCGP Learning Disability Steering Group

#### Dale Burgess

Postgraduate student FY2, PRHP

#### REFERENCES

1. Sheridan M. *The handicapped child and his home*. London: NCH, 1965.
2. Department of Health. *Valuing people: a new strategy for learning disability for the 21st century*. White Paper. Cm 5086. <http://www.archive.official-documents.co.uk/document/cm50/5086/5086.pdf>
3. Clarke D. What is learning disability? In: Roy M, Clarke D and Roy A (eds). *An introduction to learning disability psychiatry*. 2000. <http://www.lidbook.co.uk/Book.htm> (accessed 10 Jan 2006).

4. Cooper SA, Melville C, Morrison J. People with intellectual disabilities. *BMJ* 2004; **329**: 414–415.
5. The Adult Health Team. *Primary care support pack*. Nelson: Burnley Pendle and Rosendale Primary Care Trust Learning Disability Service, 2003.
6. Evans J, Mir G, Atkin K, et al. Identifying people with learning disabilities in general practice. *Living Well* 2005; **5**(3): 18–22.
7. Durvasula S, Beange H, Baker W. Mortality of people with developmental disability in Northern Sydney. *Journal of Intellectual & Developmental Disability* 2002; **27**: 255–264.
8. Wilson DN, Haire A. Health care screening for people with mental handicap living in the community. *BMJ* 1990; **301**: 1379–1381.
9. Disability Rights Commission. *Preliminary report 2005*. Stratford upon Avon: Disability Rights Commission, 2005.
10. Prasher VP, Janicki, MP. *Physical health of adults with intellectual disabilities*. Oxford: Blackwell, 2002.
11. Kerr M. Achieving health gain for people with intellectual disabilities. In: Kerr M (ed.). *Innovations in health care for people with intellectual disabilities*. Chorley: Liseux Hall Publications, 1998.
12. Aspray TJ, Francis RM, Tyrer SP, Quilliam SJ. Patients with learning disability in the community. *BMJ* 1999; **318**: 476–477.
13. Thapar A. Genetics and learning disability in innovations in health care for people with learning disabilities. In: Kerr M (ed.). *Innovations in health care for people with intellectual disabilities*. Chorley: Liseux Hall, 1998.
14. The NHS Executive. *Once a day one or more people with learning disabilities are likely to be in contact with your primary healthcare team how can you help them?* London: Department of Health, 1999.
15. Martin G. Enhanced services for patients with learning disabilities: dream or reality? *The New Generalist* 2004; **2**(3): 65–66.
16. Baxter H, Lowe K, Houston H, et al. Previously unidentified morbidity in patients with intellectual disability. *Br J Gen Pract* 2006; **56**: 00–00.

#### ADDRESS FOR CORRESPONDENCE

##### Peter Lindsay

The Thakur Practice, Suffolk Court,  
Yeadon, Leeds LS19 7JN.  
E-mail: PeterLind4@aol.com